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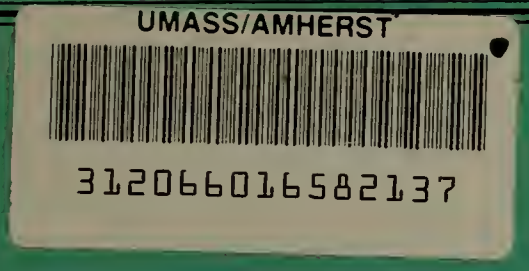

Governor's Commission on Mental Retardation

TRENDS IN COMMUNITY-BASED DAY SERVICES

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A Staff Report

TRENDS IN COMMUNITY-BASED DAY SERVICES

The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

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Trends in Community-Based Day Services

Over the past 30 years, the field of mental retardation has undergone a remarkable transformation in philosophy, organization, and practice. In sharp contrast to the inadequate, almost entirely institutionally-based services of three decades ago, community-based services now encompass a wide range of options including individualized supported living and employment. The vision of quality has been similarly transformed from a "readiness" model emphasizing the need for specialized facilities and training prior to community entry to a model promoting inclusion through the use of supports to assist persons in achieving their desired goals. Funding to meet the needs of citizens who have mental retardation remains inadequate. Unlike the budgets for other human service agencies, however, funding for the Massachusetts Department of Mental Retardation (DMR) is at an all time high.

It has been said that in our society, work is the most common, most valued, and most cost-effective way for adults with mental retardation to contribute to society (Lewis, Johnson, Bruininks, Kallsen, & Guillery, 1991). Across the nation, significant efforts have been made to increase the amount of "real work" for persons with mental retardation. Yet while the policy focus is now on community-based work opportunities, the majority of persons with mental retardation receiving services continue to attend segregated day and sheltered work programs. The situation in Massachusetts mirrors that of the nation: since 1992, the DMR has provided funding for nearly 1,200 new supported and competitive employment situations, yet more than 72% of all DMR-funded day and work services remain segregated.

The Governor's Commission on Mental Retardation was established through Executive Order in May 1993 for the purpose of monitoring "the quality and effectiveness of the Commonwealth's program of services designed to address a wide range of needs of people with mental retardation." One task in fulfilling this mandate has been to examine day and work services provided in Massachusetts. Commission members and staff met with nineteen private community-based providers. Visits were conducted to a variety of day and work settings including those that were funded by Medicaid (DMA), DMR, and Massachusetts Rehabilitation Commission (MRC). The Commission visited Adult Day Health programs and Day Habilitation programs, sheltered workshops, and supported employment sites. [See Appendix for a list of programs visited.] The purpose of the visits was not to evaluate the merits of a specific program but to engage in a constructive dialogue around key issues in the field. Specific questions were asked at each visit, but the tone of the meetings was that of an informal conversation.

This report will focus on the findings of the site visits as well as discussions with experts in the field and a review of the literature. The report is divided into three sections:

- an overview of the history and current trends in day and work services.
- a summary of findings from the field visits including concerns about staffing, quality enhancement, transportation, and obstacles to integrated employment.
- suggestions for future activity.

History and Current Trends in Day and Work Services

Historical Background Prior to the 19th century, individuals with disabilities were supported by their families in their own homes with some support from churches and local communities. The industrialization of America and significant waves of immigration resulted in a shift in attitudes towards persons who were perceived as different: no longer could the church and family be depended upon to manage problems of the community--instead active intervention was necessary for those who were "susceptible to temptation, dissipation, crime, and/or laziness" (Murphy & Rogan, 1995). This intervention took the form of segregation. Persons who were at risk were to be removed from society for the betterment of themselves and the general population. Philosophically, these separations were to be temporary; in practice, they were often permanent. Needy persons were divided into two groups: those who were deemed incapable of caring for themselves were to be cared for at almshouses, and those who could be trained to become useful (i.e. able to work) members of society were to be assigned to workhouses. Concerns about the almshouse-workhouse system emerged in the late 1800s, and this "Progressive Movement" viewed persons with disabilities as helpless individuals who required lifelong, paternal protection and guidance. These three notions: the idea of segregation for the common good, the distinction between those who could and could not work, and the attitude that persons with significant disabilities were helpless all served as a foundation upon which disabilities services were constructed.

It is generally agreed that the first sheltered workshop was founded by Samuel Gridley Howe, Director of what is now called the Perkins School for the Blind in Massachusetts. Significantly, even in this era, Howe was mindful of the risks of segregation. Writing in 1849, he stated: "It should be a cardinal principle of the education of the blind to keep ever in view the fact that they are to become members of general society and not a society of blind people..." (cited in Murphy &

*A **sheltered workshop** is "a charitable organization or institution conducted not-for-profit, but for the purpose of carrying out a recognized program of rehabilitation for handicapped workers, and/or providing such individuals with remunerative employment or other occupational rehabilitating activity of an educational or therapeutic nature"* (Federal Register, May 17, 1974, p. 17,509).

Rogan, 1995). This notion that a sheltered setting is a first step towards a productive community life was later refined and called the "readiness model" whereby sheltered activities were a means to practice skills which could later be used in the community. Sheltered workshops continued to grow throughout the next century, and these facilities were often the *sole* community-based service for persons with disabilities.

Beginning in the 1960s, families began to seek out community-based services for their children and youth with mental retardation. They developed activity programs through volunteer efforts and private fundraising. With the passage of Chapter 766 in 1972, some of these young people entered the public school system to receive special education services to which they were newly entitled. State funding for adult services gradually increased, and adult day activity centers and sheltered workshops emerged as the primary service delivery models. Daily reimbursement for these early programs was astoundingly low with sheltered work funded at $8.50 and day activities $12.50 per day per client.

The advocacy of family members who sought additional services for their loved ones was supported by federal legislation. The Rehabilitation Act of 1973 (PL 93-112) mandated the extension of rehabilitation services to persons with severe disabilities and extended constitutional protection for equal employment opportunity for all persons with disabilities. Both research and advocacy focused on convincing society that all people, regardless of the intensity of disability, could learn if given the opportunity. The renewed commitment to persons with developmental disabilities has been characterized as an "Era of Optimism." "This optimism spawned a sense of idealism that made the normalization principle seem not only possible but inevitable" (Bradley, 1994). One of the pioneers was Marc Gold who conducted training forums which were impassioned demonstrations of the power of effective teaching:

> *Gold's most convincing demonstration came when a young man with obvious severe spasticity and mental retardation (the kind of person professionals usually passed off quickly as "not feasible for employment") was slowly helped to the stage. The young man, whom Gold had just met a few minutes earlier, sat down at a table in front of a 15-compartment tray containing the sorted parts of a Bendix 70 bicycle brake. Gold positioned*

himself in a chair to the left of the man and slightly behind him. Then with a little talking, Marc reached forward, took an axle from the first compartment, and step by step added parts from each of the other bins until he held a fully assembled bicycle brake. With a confident "Lookie there" he sent the brake assembly spinning around the axle.

Round two. With Gold's hands over the man's hands, all eyes focusing on the bicycle parts, they assembled a brake together.

Round three. The man was gently encouraged to assemble a brake himself. Then Gold's hands were less involved, and when a part fitted on the axle wrong, Gold quietly said, "Try another way." The man did so, and the process continued until the assembly was complete.

Round four. The young man successfully put a brake together himself, spun on the axle, and broke into a broad grin. (Perske, in McLoughlin, Garner & Callahan, 1994, p. *vii*.)

Trend toward supported employment The 1980s saw a national shift toward integrated employment for persons with significant disabilities. The Education of the Handicapped Amendments of 1983 (PL 98-199) addressed the lack of transitional assistance for persons leaving special education. New funding for time-limited services became available through the 1986 amendments to the Rehabilitation Act (PL 99-506). Initial pilot programs documented impressive results, and many sheltered workshops added a supported employment component. Four program models emerged:

- **individual placement** where an employment specialist or job coach helps develop a job, trains the worker, and then fades from the site when the worker is ready for independence. This continues to be the most highly utilized model of supported employment, yet persons with significant disabilities comprise only a small percentage of those who receive this type of support. Individual placements can be cost-effective when compared to sheltered settings if the job coaching can be time-limited.

- **enclave model** is a group supported employment site where permanent, on-site staff supervises workers with disabilities. This model is cost-effective especially for persons who require long-term supervision. Initially, this model was viewed as one which promoted social inclusion, but recent studies show that persons in an enclave have limited social contacts with other employees.
- **mobile work crews** are small, mobile businesses in which groups of persons with disabilities travel to do cleaning, janitorial, groundskeeping, and light assembly tasks. Staff generally remain with the crew. Social inclusion is limited by this model because workers are segregated and not permanent members of a business.

> ***Supported employment*** *is..."paid work in a variety of settings; particularly regular work sites, especially designed for a handicapped individual for whom competitive employment at or above minimum wage is unlikely; and (ii) who, because of the disability, needs intensive, on-going support to perform in a work setting* (Federal Register, September 25, 1984, Section 102, [11],[F].

- **entrepreneurial model** is similar to the enclave and mobile crew. Workers go to a fixed site; some models integrate disabled and non-disabled workers at the same location.

Goals for these new programs initially focused almost exclusively on achieving higher earnings through increased wages and longer hours of paid work. As the field of supported employment developed, quality of life issues came to the forefront especially the values of community integration and enhanced social roles. "Financial criteria cannot be the sole measure of the value of employment because most workers derive benefits from working other than the earnings reported on a wages and tax statement" (McLoughlin, Garner & Callahan, 1994).

Supported employment opportunities have been the most visible and rapidly growing method of assisting persons with mental retardation to be included in society. Between 1986 and 1988, there was a 226% increase in supported employment nationally, and by 1989, over 32,000 persons were served through this model (Wehman, Kregel, & Shafer, 1989). While few other initiatives have undergone such remarkable growth, opportunities remained scarce, and the number

of sheltered placements also continued to grow. Nationally, in 1989, only 5-6% of persons with mental retardation were in supported employment (Lakin, Hill, Chen, & Stephens, 1989). Perhaps even more significant, less than 10% of adult day programs have downsized or reallocated resources (Wehman and Kregel, 1994). Thus, supported employment typically functions as an additional component to segregated services rather than as a tool which reduces reliance on segregated settings.

The rapid expansion of supported employment in the 1980s led many to believe that similar increases would extend into the 1990s. Federal legislation again supported the expansion of community-based employment through the Rehabilitation Act of 1992 which removed the "employability" standard for eligibility. But instead of the rapid and permanent replacement of segregated work as called for by organizations such as TASH in 1989, growth of supported employment has reached a plateau in this decade. The Training and Research Institute based at Children's Hospital in Boston undertook a national survey of integrated employment (McGaughey, Kiernan, McNally, and Gilmore, 1993). With 41 state MR/DD agencies (80%) providing data, they found a substantial (5%) increase in overall numbers of persons served in integrated employment settings between 1989 and 1991. Yet this was also accompanied by a continued emphasis on segregated settings: 44% of all those served attended sheltered work settings and 37% attended non-work day programs. Further, many persons with less significant disabilities remained in segregated settings: 48% of all those in day programs and 68% of all those in sheltered work had mild or moderate mental retardation.

One reason why segregated day services continue to dominate is the restrictions on the use of federal Medicaid dollars. 63% of all day service dollars come from state MR/DD funds, however the next largest percentage--25%--come from federal Medicaid grants. These funds go to non-work services such as Day Habilitation programs. The HCBS waiver funds may also be used for pre-vocational services and supported employment but only for those persons who are currently living in ICFs-MR or who have previously been institutionalized (i.e. those who require the intensity of supports offered by the ICF-MR but have never lived in such a facility are not eligible for HCBS funds to pay for supported employment). In FY'90, the preponderance of HCBS spending was devoted to non-work programs: 84% of waiver funds went to Day Habilitation services, 11% went to pre-vocational work activity centers, and only 5% went to supported employment.

Higher than anticipated costs of supported employment have also limited expansion of the services. The early supported employment programs promoted the service model of the time-limited job coach. A trained staff person would accompany the worker to the paid placement, provide intensive training, and then fade involvement. This model of time-limited support was viewed as cost-effective in comparison to a sheltered work setting with permanent staff supervision. However, the difficulties with fading the job coach led to more long-term staff supports which increased costs.

One response to the cost of permanent staff on the job site has been to re-examine the role of paid and un-paid supports. There is a growing opinion that the long-term presence of paid staff is detrimental to the social integration of persons with mental retardation and to the willingness of co-workers to provide both spontaneous and sustained support. Newer models of on-the-job supports view the job coach as a resource to the worksite, to train co-workers and direct supervisors and to assist with problem resolution. By involving the co-workers, employers, and others directly supporting the individual and using the job coach primarily as a resource, long-term placement of staff on-site is avoided.

Another response to the high cost of supported employment has been a renewed emphasis on self-determination. Studies of family-controlled supports have demonstrated the efficiency of families to purchase the goods and services they need (Smith, 1994). By empowering the person with a disability and his or her team to control work related supports, it is anticipated that this same cost-efficiency will be replicated. It is also suggested that if individuals control their own supports, persons providing paid supports will have established connections with those individuals, thus enhancing social integration.

Finally, both the slow growth in supported employment and continued growth in sheltered settings have renewed the call to stop funding sheltered settings. Many assert that the perpetuation of the sheltered settings limit expansion of integrated settings because funds which could be used for job development go to fixed facility-based costs (Albin, Rhodes, & Mank, 1994; Lewis, Johnson, Bruininks, Kallsen, & Guillery, 1991; Mank, 1994; Murphy & Rogan, 1995). More fundamentally, the sheltered setting is now often viewed as incapable of meeting the needs of persons with disabilities. Murphy and Rogan (1995) assert: "It seems clear that sheltered

workshops cannot meet the rapidly changing demands that people with disabilities, their families, and a growing number of professionals are making regarding personal choice, control of services, and integrated work. Because exclusion and professional control are integral to the workshop concept, they render workshops culturally, structurally, and functionally anachronistic" (p. 33). Although this theme is commonly sounded in the literature, there is little evidence that action is being taken. Wehman and Kregel report in 1994 that fewer than 5% of adult day programs have eliminated segregated settings.

Trends in Massachusetts

Rapid expansion in community services Since 1992, the Commonwealth has undergone a dramatic expansion in community-based services. All types of day and work services have expanded during the past four years including both Medicaid and DMR-funded day programs. All day services--both work and non-work oriented--have increased by a total of 37% (see Figure 1).

Persons Receiving Services Funded by DMA and DMR in Massachusetts
Figure 1

Program Model	1992	1996	% increase
Day Habilitation (DMA Funded)	1050	2007	91%
Day Activity/ Sheltered Work	6774	8245	22%
Supported Employment	1403	2504	78%
Competitive Employment	637	721	13%
Total	9864	13477	37%

(Data Sources, DMR FY'96 Annual Report, 1992 Day Hab figures are from Braddock et al., 1995; 1996 Day Hab figures are from oral communication with the Division of Medical Assistance.)

Expansion in Supported Employment Massachusetts has doubled its spending for supported employment since 1992 resulting in significant gains in integrated employment opportunities--a 78% increase in less than five years. This expansion has been a critical issue for the leadership of the DMR. In the past two years, three of the agency's twelve management goals were directed at enhancing integrated employment. In each of the three areas, the results have surpassed the goal by between 22% and 120% (See Figure 2).

The re-orientation of day services to integrated employment is impressive especially given the restrictions on federal reimbursement for long-term supported employment and the 19% decrease in overall state funding (in inflation adjusted terms) for MR services during this same time period (Braddock & Hemp, 1996). Although Massachusetts has made significant gains in its supported employment opportunities, it continues to lag behind its New England neighbors including Vermont, New Hampshire, and Connecticut. In Massachusetts, per capita spending on supported employment is currently $3.41. Vermont, New Hampshire, and Connecticut all spent over $5.00 in 1996 (Braddock & Hemp, 1996). As with most of the nation, in Massachusetts the preponderance of day services remain segregated, with over 75% of DMA and DMR services offered in segregated settings (See Figure 3).

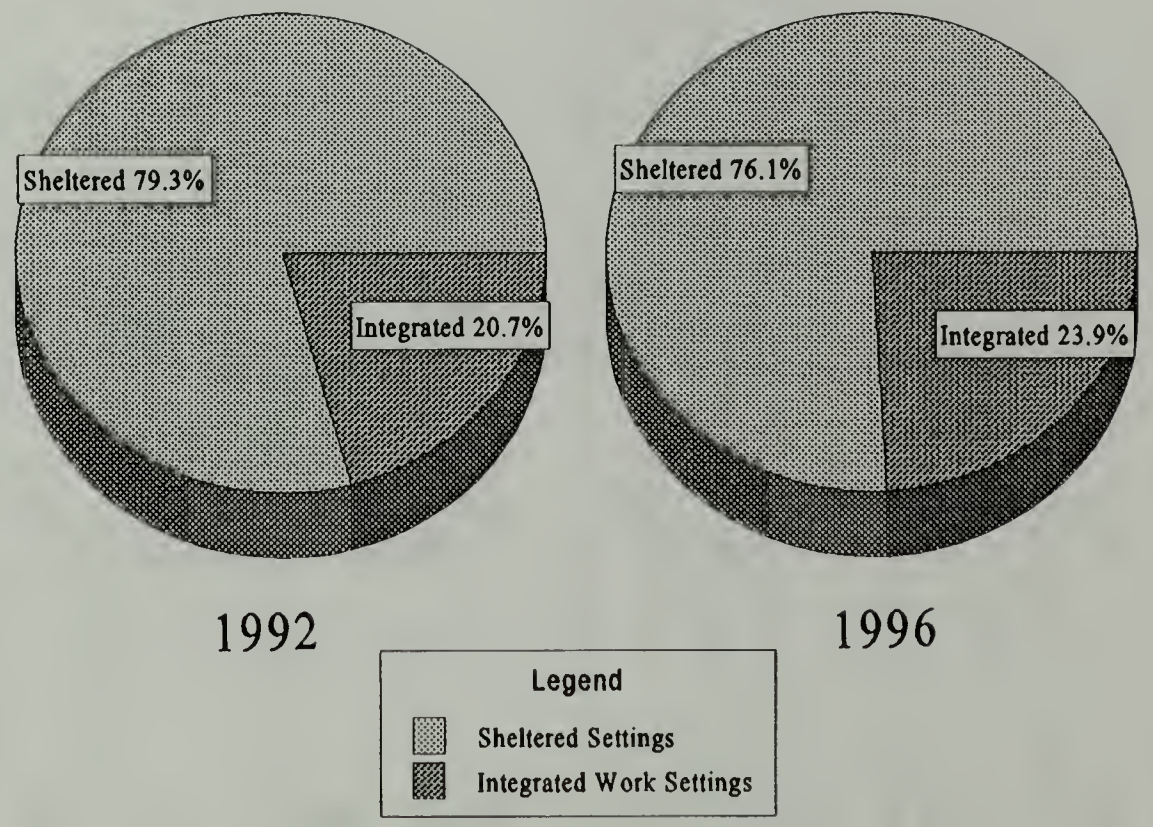
DMR FY'96 MANAGEMENT GOALS (#1-3)

Figure 2

GOALS	Region I		Region II		Region III		Region V		Region VI		TOTAL	
	goal	actual	goal	actual	goal	actual	goal	actual	goal	actual	goal	actual
1. Integrated Employment for people in sheltered workshops (provider paid, may include enclaves and work crews).	35	77	110	156	45	119	83	246	85	192	358	790
2. Employer paid supported employment for people in sheltered workshops.	31	48	76	122	46	65	90	93	65	65	308	393
3. Divert sheltered workshop placements for new consumers to integrated employment.	8	11	18	18	18	44	16	15	30	22	90	110

MA Trends in Employment 1992 & 1996

Figure 3



Sheltered Settings include Day Habilitation, Education and Training, and Sheltered Work settings funded by Medicaid (DMA) and DMR.
Integrated Settings include DMR funded Supported and Competitive Employment

Themes from the Site Visits

Staff and members of the Governor's Commission on Mental Retardation met with nineteen providers of day and work services. At times the meetings were with the executive director alone, but more typically the meetings were held with a group of senior and middle managers and often with direct service staff and users of the service. The Commission found that most providers were eager to talk about both the struggles and satisfaction of their work. Although these organizations often offered a diverse range of services, Commission members and staff encountered a surprising amount of consensus regarding both accomplishments and on-going concerns. This section of the report will review the four most prevalent themes from the site visits: direct service staff, quality enhancement, transportation, and obstacles to integrated employment.

Direct service staff--salaries, turnover and training Without doubt, the single biggest concern among providers was the *low salaries* for direct service workers. During the course of the interviews, the Commission met dedicated young staff persons who revealed that their full-time job in day services was often only one of several. One gentleman carried a full college course load while working at one full-time and two part-time jobs. This earned him about $25,000 annually and a room in a group residence as a live-in staff person. Working so many hours created challenges for these individuals to attend trainings and participate in evening meetings. More significantly, very few of the young persons intended to make human services a career. As one executive director, who pays her entry level workers $19,000 (with the state average at $16,500), told the Commission: "If you want quality service--committed people who are well-educated and concerned about the quality of life in addition to client safety, something must be done about salaries!"

In their significant study of wages and staff turnover, Mitchell and Braddock (1992) note that the low pay of direct service workers has a longstanding history. They cite an example from 1912 in which "notoriously insufficient pay" was viewed as the major reason why staff turnover was running at 70% in New York Institutions (p. 290). Mitchell and Braddock cite reasons for low direct service wages. They include: gender bias, in that women earn less than men and mental retardation services are dominated by women, low social value to "caretaking" work, and the field's historic roots to private charities that have always paid near poverty wages.

This study also noted the dramatic difference between public and private wages with state workers earning an average of 46% more than those employed by private agencies. This substantial difference was due primarily to step increases available to long-term employees in most state systems which were generally not available to those in private agencies. Few providers that the Commission visited rewarded longevity of service with pay increases. The absence of such increases was exemplified in the case of one woman who, as a college graduate with a degree in special education working in the field for nearly twenty years, earned only $20,000 annually. This woman commented that she and her husband feel that they make a "charitable contribution of $15,000 per year" to persons with mental retardation--the difference between her actual wages and what she would earn as a school teacher. Several providers did attempt to promote longevity of service through less costly incentives such as increased vacation time, access to training, and employee recognition.

Turnover rates for direct service staff ranged from 31-71% annually in the Mitchell and Braddock study. The providers the Commission met with did not experience such high levels of turnover in their day services, however, many commented that turnover in their residential contracts--with its abundance of evening and weekend hours--often reached rates of 50% or more. The level of direct service turnover varied from agency to agency. Significantly, salary and geographical location did not have as great an impact on turnover as type of service offered. Smaller, individualized agencies which provided only integrated employment had little trouble keeping staff. People who worked for these organizations frequently noted that they had found their "niche" and planned to remain in their current position. One small program which has no "facility" for day services also has essentially no turnover, with many persons remaining in their current jobs for five or more years. Recent studies have noted high levels of satisfaction among supported employment specialists (Parent, Gibson, Unger & Clements, 1994), and the turnover rates at the integrated employment services the Commission visited support these data.

The Commission staff and members were pleasantly surprised to encounter a significant commitment to staff *training*. The leadership of each agency recognized the importance of such training and appeared to have the internal capacity to provide at least the mandatory trainings which include First Aid and CPR, safety training, medication administration, Human Rights and ISP training. Many providers used a

competency-based system whereby new employees complete all the mandatory trainings during the first three months of employment. Most used a combination of on-site training by the individual supervisor as well as classroom-based sessions. Some providers pooled training dollars to maximize their benefit. Others made a substantial commitment to on-going skill development through mandatory annual training requirements. Although the mandatory training seemed to be well managed, providers expressed dismay about the high cost of the 16 hour medication administration training. Some felt that this "unfunded mandate" exhausted training budgets and focused staff training almost entirely on health/safety measures rather than on developing the skills needed to support self-determination, choice making, and inclusion. For providers who had high turnover rates, there was concern about the ceaseless aspect of training. Given the intensive initial investment in staff training, the benefits of an experienced staff were never realized because many of the workers left the agency soon after the training was completed.

Other providers expressed concern that the "paradigm shift" from services to individualized supports would dramatically increase staff responsibility and independence and thus increase the need for intensive training. One executive director noted that "People working more independently in smaller settings will need a whole new array of skills, and they won't get the benefit of working side-by-side with more experienced workers as role models." Many nationally recognized leaders concur that training will have to be significantly intensified if the individualized model is to be fully implemented. In 1993, the Boston-based Institute for Community Inclusion conducted a statewide survey of supported employment specialists and their managers ("Developing Quality," 1993). Their survey noted that 92% of respondents ranked further training as an "overwhelming interest." Nearly one half of program managers and employment specialists indicated that they had received no training in supported employment practices from their agency. Training topics of interest included: working with the business community and job development especially for persons with more significant challenges, involving consumers in individual service design and delivery, and developing program goals that support community employment and sufficient funding.

A national review of skill standard initiatives noted that qualifications for direct service employment vary significantly from state to state. Some states require mandatory certification and training for its direct service workers; other states permit local private agencies to determine and deliver their own training. Direct service workers in some states must have some college course work; others require a high school diploma or GED; still others pose no educational requirements (Jaskulski & Ebenstein, 1996). In Massachusetts, a high school diploma or GED is required. Work experience requirements differ among agencies.

The federal Department of Education selected the Human Services Research Institute (HSRI) to develop skill standards for direct service workers. Through a series of two day workshops in which direct service workers described the nature of their work and what skills were required, standards for a core group of skills for all direct service workers (regardless of job title or population served) was developed. The purpose of these skill standards is both to assist the direct service worker and his or her agency to develop and measure skills as well as to support family members and users of a service to assess the qualifications and competency of the workers involved in their support.

*The **National Skill Standard Competency Areas** include:*

- *participant empowerment;*
- *communication;*
- *assessment;*
- *community and service networking;*
- *facilitation of services;*
- *community living and supports;*
- *education, training, and self-development;*
- *advocacy;*
- *vocational, educational, and career support;*
- *crisis intervention;*
- *organizational participation;*
- *documentation.*

Quality enhancement--the dual systems of CARF and QUEST

Tremendous amounts of time and funding have been devoted to the assessment and monitoring of services for persons with mental retardation. This is particularly true in states, such as Massachusetts, which have been subject to lengthy consent decrees. Massachusetts had devoted many of its quality assurance efforts to measuring the "inputs" and "outputs" of a particular program--that is, DMR licensed

its providers based on the safety of their physical facilities, the number and training of their staff, and their capacity to provide services to a given number of persons. The DMR recognized that the specific focus on health, safety, rights, and ISP implementation was an inadequate means of "buying" quality, and it abandoned the old licensing system in 1994. In its place was a certification process based on the Quality Enhancement Survey Tool (QUEST). All DMR-funded day services must now be certified by the QUEST survey. Because Day Habilitation funding comes from Medicaid (not DMR), these programs do not undergo QUEST. Instead, the Day Habilitation provider must pay for a quality assurance survey from one of two national evaluation processes: CARF--the Rehabilitation Accreditation Commission or the Accreditation Council. Site visits are also conducted by the DMA. Currently, no Day Habilitation provider uses the Accreditation Council survey which, like the QUEST, is an outcomes-based measure. While the CARF evaluation has recently been revised to better address the need for providers to "manage outcomes," it remains a traditional measurement of inputs and outputs--that is, of the delivery of services rather than the results of those services. It also continues to evaluate programs rather than the recipients' services, achievements, or satisfaction.

*The **DMR QUEST survey** is divided into six major quality of life areas which reflect those aspects of living that would be considered quality in the lives of all people. They are:*

- *Respect and Dignity*
- *Individual Control*
- *Community Membership*
- *Relationships*
- *Personal Growth and Accomplishments*
- *Personal Well-Being.*

Nearly all Day Habilitation providers also provide DMR-funded day services. In fact, Day Hab sites are often located in proximity to sheltered work settings. Thus, a single agency often has its day services assessed by two very different types of tools--and apparently with quite different results. Several providers the Commission met with held the highest level of CARF accreditation for their Day Hab settings, but their DMR-funded programs were only certified conditionally by QUEST.

Attitudes toward CARF and QUEST Providers of Day Habilitation services are uniformly satisfied with the CARF system. They find it objective, timely, and consistent. The values of QUEST also received universal praise, but providers expressed concerns about the implementation of the program especially during the initial certification process. Early on in the site visits, the Commission encountered complaints about the training of the QUEST surveyors, and several providers suggested that the QUEST pilot should have been continued for a full year before it was implemented.

Several providers noted that the QUEST survey was more applicable to residential services than day services, and they felt that separate tools for each type of service would be valuable. Commission staff met with June Rowe, Director of Survey and Certification, DMR, to review these concerns. She reported that a separate tool had been considered in the design of QUEST, however, it was decided that a "whole-life" tool better integrated the values of the DMR Mission statement. In addition, the QUEST tool has been refined so that certain sections (such as the part about making friends) can be "not rated" by the QUEST surveyors of day programs. Several providers of both residential and day services noted that day services received less evaluation and comment in the reports and oral feedback. June Rowe also agreed that the residential component received more attention in the initial survey, but a better balance had been achieved in the re-certification process. Because so few agencies have been re-certified, it is hard for this to be assessed, but in one report reviewed, a better balance was achieved.

Several providers also suggested that there should be distinct categories for agencies who are under conditional certification due to safety or human rights concerns and those who receive conditional certification due to stagnation in their efforts to promote community membership or individual control.

Transportation Not surprisingly, concerns about transportation to and from work and day programs were multiple--in fact for several providers, transportation was the number one "headache issue."

Transportation as the key to job development In September 1995, the Governor's Commission on Mental Retardation sponsored a public hearing on transportation. During the hearing, Pamela Sampson from Alternatives Unlimited noted that "Transportation is one of the most challenging aspects of getting people

jobs in the community because public transportation is not readily available.... Employment opportunities are tied to people's transportation rather than the needs of the employee or the employer." This concern captures the fundamental necessity of having adequate transportation in order to make "real work" possible. All providers who had successful individualized employment services also had the capacity to provide individualized transportation. This was generally done by employment specialists who used their own cars or, in urban areas, via public transportation.

During the site visits, one provider noted the necessity of re-thinking the notion of "providing" transportation. He had recently re-convened a summer "school-to-work" training program in which no transportation was provided due to budget cuts. Families who enrolled their adolescent children in this training agreed to provide the transportation. Each family did so, often through flexible, "natural" solutions such as car-pooling with neighbors. This provider noted that "we had never considered making such a demand on families, but now we have to begin thinking about it."

Concerns about transportation provided by others Increasingly over the years, the Regional Transportation Authorities (RTAs) have coordinated transportation for citizens who have mental retardation. Some providers viewed this as a positive, cost-effective strategy. One executive director noted that some regular bus routes had been changed to better accommodate his clients' needs. Vans leased by the local Council on Aging were now used to provide transportation for his clients which he felt was a good use of resources. Another provider, who held DMR-funded day, residential, and transportation contracts, expressed concern about the RTAs. This provider experienced difficulty with drivers not providing door-to-door transportation in bad weather. She gave an example of one client who on a snowy day was dropped off at the end of his street to walk to his residence when he was not to be left alone in the community. Another example involved a person with mobility challenges who had to walk across an icy parking lot instead of being dropped off in front of the work place.

Several providers mentioned that transportation companies do not adequately train their drivers or monitors. This was especially troublesome for those providers who supported people with significant behavioral challenges. Incident reports were not filed, and clients came into day programs upset following difficult van rides. One provider noted that the RTA had now taken on the

management of transportation of very challenging clients. This is a "specialty service" which requires training for the drivers and monitors on those vehicles. This training was not provided. Further evidence of this lack of training is also found in the Seaside Education Associates, Inc. Report on Transportation (November, 1995). While this report, commissioned by the DMR Office on Quality Enhancement, noted that both consumers and families are highly satisfied with transportation in general, it also noted that 25% of drivers did not receive the training that was mandated by the Department's contract. 35% of monitors assigned to vehicles to promote client safety had not received the necessary training.

For site-based day programs, staff spoke frequently about their frustration with inconsistency in drop off and pick up times. This was especially taxing for direct service workers who often needed to leave on time for school or a second job. Senior staff spoke of their difficulties in providing the contractually managed staff ratios when their programs were functionally staffed for as much as 90 minutes longer each day due to late transportation. In addition, because staff usually do not receive overtime for staying late but are given compensatory time off later in the week, transportation delays often made significant impacts on regular program time as well. One provider was diligent in providing activities for very behaviorally challenged clients who were waiting for transportation, but this was accomplished at the expense of staff meetings and training time.

Concerns when transportation is provided by the provider Over the past few years, the DMR has increasingly contracted for transportation directly with the agency who provides the day service. Many recognize the quality advantages of this system, especially because staff who are trained and well known to the client also provide the transportation. However, taking on this project has been a monumental task for some agencies. Leaders of the provider organizations were especially worried about the potential rise in workers' compensation rates if their direct service workers became classified as drivers. One provider noted that the current workers' compensation rate was between $2-4 per $100 of insurance. This rate would balloon to between $9-10 per $100 if her workers were classified as drivers. In addition, it was noted that when direct service workers take on the responsibility of transporting clients, they risk a dramatic increase in the cost of their personal auto insurance, because they are now using their car for work-related activities.

Obstacles to Integrated Employment Significantly, providers were united in their opinion that integrated employment is the best option for most persons with disabilities. Regardless of whether a provider had most of its employees on-site or in integrated employment settings, the value of integrated employment was universally affirmed. Providers discussed a myriad of obstacles to creating more integrated, "real work" placements. These concerns focused on funding restrictions and overall costs, family and community resistance.

Funding restrictions By definition, Medicaid-funded Day Habilitation programs are located at a fixed site and are not work-oriented. Not only must a program participant be unpaid for his or her activities, the focus of these programs must be on therapy and skill development rather than work. With over 2,000 participants in the Commonwealth attending these programs, this limitation has a profound impact. In addition, because of significant DMR waiting lists, Day Habilitation slots are often the only available option for day services. Some providers have been able to work around Medicaid restrictions by providing unpaid opportunities (i.e. "selling" craft items through requested donation and other volunteer work). Others have worked with DMR to provide a few hours per day or week of DMR-funded support which allows for paid work. Most of this paid work is in a workshop, but there are examples of persons with significant disabilities working in individualized, off-site placements for 2-3 hour shifts and then returning to the Day Hab setting for therapy and group work.

While there was a consensus among providers that integrated employment was a valued, realistic choice for their clients, no provider felt that supported employment could be significantly expanded without a major infusion of funding. When the concept of supported employment was initially advocated, program developers assumed that individualized job coaching would be time limited and thus a cost-effective alternative to the sheltered work setting. The reliance on individual long-term paid support dramatically expands the cost of services. The providers estimated that it would cost at least twice as much to provide long-term on-site job coaching in 1:2 ratio as it would to provide a sheltered setting. One provider exclaimed: "Give me $15,000 per year [per person], and I'll get everyone out!" The literature reports that individualized job development that relies on natural supports in the workplace has been effective, but most providers interviewed felt that their clients' needs were too intense to rely on unpaid supports.

"Day custody" Providers often expressed concern that they were mandated to provide two very different kinds of services. One was to provide a type of "day custody," consisting of safe supervision for 30 hours per week (five six hour days); the other was to promote job training and job placement. These disparate activities often conflicted with one another. Entry level jobs were usually part time and often included evening and weekend hours. If the person receiving support could not stay alone either in the family home or in the group residence, it was often impossible to work outside the typical 9am-3pm workday. Several providers noted that if the person lived in a group residence, they did not even attempt to develop a job outside of the 9am-3pm schedule, because there was never enough flexibility in residential staffing patterns to permit this.

Family concerns about security Some providers found that family members were very reluctant to have their loved ones outside of the sheltered setting. Families were concerned about the loss of the social network of the sheltered workshop; they worried that their family members would be teased or traumatized in an inclusive setting. Other family members were more open to the notion of "real work" but wanted assurances that their loved ones not earn enough money to jeopardize their SSI or MassHealth benefits. Other providers found little resistance to integrated employment. One noted that only one out of his 64 clients was "held back" because of his mother's concern about the loss of the SSI check. Another noted that there was a need for the provider to "hold the family's hand" through this process, but as long as support was given, family reluctance was not insurmountable. Providers who offered only integrated employment services encountered no resistance at all because "real work" was the only service option.

Community Obstacles Several providers suggested that *economic downturns* hit their consumers the hardest. One provider in Southeastern Massachusetts noted that at one point all his clients were out working in integrated settings, but due to several major economic cutbacks in his region, 25% were now working in the sheltered setting. Many providers said that employers were willing to hire persons with disabilities, but they were dependent on long-term job coaching, because employers insisted on having agency staff present permanently. Several providers also noted that businesses much preferred to sub-contract work to the workshop rather than have disabled workers come to the business to do the work. Nor was the Americans with Disabilities Act (ADA) viewed as helpful. One provider noted that he had found that the ADA hurt his clients, recounting a conversation with a major employer who said, "If I hire them, I'll never be able to fire them."

Staff resistance Most agencies provided both sheltered and integrated services, and some found staff reluctance a significant issue. One provider noted that middle managers had the most difficult time seeing the possibility of real change, while direct service workers could see the potential of their clients. Another provider noted that she had spent too much time "bringing people along" rather than stating that integrated employment was the new organizational standard and letting staff leave if they were unhappy with the new direction.

Communication of expectations Several providers noted that DMR had difficulty responding positively to significant movements towards integration. One noted that he now had half of his clients in the community, reducing his facility needs by 50% with no recognition by DMR of his achievement. Another noted with chagrin that clients who set up a coffee shop in a rest home and were paid a stipend out of provider funds were not considered employed by the DMR even though their social inclusion and active work had dramatically improved. One provider who was actively seeking to increase integrated employment found that DMR communicated mixed messages to vocational providers. On the one hand, Central Office DMR was clear about expanding integrated employment offerings while the local and regional offices persisted in referring clients to the sheltered settings. She noted that she would never be able to "close the shop" unless she was given a real mandate to cut off admissions to the site-based program.

Findings

Day services remain segregated. Both the literature and the Commission's site visits repeatedly demonstrate that if the proper supports are provided, real community work is possible for most persons with mental retardation, including those with severe disabilities. While the success of the initial supported employment programs has been widely communicated, their positive outcomes have affected the vision of quality more than practice. Even in Massachusetts, where DMR funding has expanded supported and competitive employment by over 75% in five years, most citizens who receive day services remain in segregated settings. The reasons for this are:

- Federal regulations direct the use of Medicaid dollars to non-work settings.

- The costs of long-term individualized job coaching are prohibitive. In the current system, the day service is implicitly required to provide two disparate activities: to provide a safe, supervised environment for 30 hours per week and individualized job training in a community setting. Current reimbursement for these dual activities is inadequate.

- Supported Employment has been viewed as an additional service rather than an alternative to traditional sheltered work.

Day Habilitation centers are accredited by a system that places less emphasis on inclusion than the QUEST does. The Day Habilitation centers, which are often located along side DMR-funded sheltered work programs, undergo quality assurance evaluations which significantly differ from those of the DMR-funded programs. The QUEST examines a broad range of quality outcomes for individual recipients of services including the extent to which social inclusion is promoted. CARF, the survey tool for Day Habilitation sites, focuses on program offerings, not the results of those services.

Providers are struggling with a myriad of priorities and often function at or near "crisis mode." This situation limits an organization's ability to successfully operate and plan for the future. Particular difficulties include:

- Low entry level salaries limit a provider's ability to have an experienced, trained staff. As programs become more individualized, well trained staff who are able to function autonomously will be crucial.

- Transportation delays create on-going stress which impacts the quality of programming and impedes training time.

Action Steps:

- **Highlight low cost (i.e. same cost) ways to provide integrated employment.** The goal of community-based employment is universally embraced throughout Massachusetts. That there is consensus regarding the goal is heartening, but the implementation of these values is clearly an unmet challenge. Some agencies have demonstrated that increases in integrated employment without increased costs are possible. These practices need to be analyzed and shared with all providers.

- **Evaluate Day Habilitation programs using outcomes-based tools such as the Accreditation Council or the DMR QUEST.** Day Hab programs will continue to play a significant role in the continuum of services for the foreseeable future. Using the QUEST or the Accreditation Council will not help the over 2,000 persons who attend Day Habs gain employment, but these quality evaluations will require providers to devote funds and staffing to enhance social inclusion.

- **Continue the commitment to raise base direct service salaries.** Providers were unanimous in their assertion that low direct service salaries were the single biggest obstacle in maintaining high quality services. Throughout the site visits, the Commission met with staff dedicated to doing quality work, yet the conditions under which they worked hampered their capacity to become long-term contributors to the field of mental retardation. The best and the brightest direct service workers often left the field upon completion of their education due to insufficient wages.

Appendix

Programs Visited

Region I
FOR Community Services, Inc./Sunshine Village
New England Business Associates

Region II
Alternatives Unlimited, Inc.
Barry L. Price Rehabilitation Center, Inc.
Horace Mann Educational Associates, Inc.
Riverside Community Mental Health and Retardation Center, Inc.
Toward Independent Living and Learning (TILL), Inc.

Region III
Bass River, Inc.
Central Middlesex Association for Retarded Citizens (Cmarc)
Shore Educational Collaborative

Region V
Attleboro Enterprises, Inc.
Brockton Area Multi Services, Inc.
Community Connections, Inc.
Nemasket Group, Inc.
Road to Responsibility, Inc.

Region VI
Charles River Association for Retarded Citizens (Charles River Arc)
Commonwealth Business Associates of Transitional Resources, Inc.
Greater Waltham Association for Retarded Citizens, Inc. (GWARC)
Eliot Community Human Services, Inc., Kelleher Center

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